



Independent Agenda Aging Event

Name of Event: Caregiving and Mental Health: A Multi-Dimensional Issue

Date of Event: Friday, September 16, 2005

Location of Event: Brooklyn College Student Union, Brooklyn, New York

Number of Persons attending: 130+

Sponsoring Organizations: Greater Southern Brooklyn Health Coalition, New York City Department for the Aging, Brooklyn College, Center for the Study of Brooklyn, Pfizer, and AARP-New York.

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On Friday, September 16th, over 130 providers of aging services, advocates, and caregivers came together to talk about the multitude of issues confronting caregivers and the impacts on their mental health. The day was informational and provided an opportunity for speakers and participants to discuss issues that need further research, discussion, and policy.

Priority Issue #1: Addressing Cost of Care

- According to the National Family Caregivers Association, more than 50 million family caregivers across the country provide services valued at \$250 Billion annually.
- Part-time custodial care can cost well over \$20,000 annually while 24-hour home care is almost as expensive as nursing home care. Nursing homes, which average \$80,000 per year in NY, can run as high as \$125,000.
- Family caregivers sacrifice time and wages to care for loved ones, and over their lifetime can lose an average of six hundred and sixty thousand dollars (\$660,000) in combined social security benefits, pension benefits, and wages.
- Under the Family Medical Leave Act (FMLA), companies with more than 50 employees are required to give employees up to 12 weeks of paid or unpaid leave to care for a sick family member. However, there is no option available for an individual who is not eligible for FMLA.
- Many older adults who are capable of participating in the less expensive and restrictive social model have been placed in the more expensive medical model because it is fully covered by Medicaid. (Medical model adult day care, which Medicaid reimburses the facility \$130 a day.)

Barriers:

The barriers to addressing cost of care include:

- Medicare covers predominately acute care needs. Medicaid pays for long-term care but a family must spend down almost all of its assets before becoming eligible for Medicaid.
- With nearly one out of every four US households providing care to an older relative or friend, an invisible healthcare workforce is providing approximately 80% of all homecare services. Services are being provided by caregivers, who literally, are underpinning our healthcare system.
- The impact of family caregiving can also be seen in the workplace, where it is estimated that caregiving is costing American businesses between \$11 to \$29 billion annually in lost productivity.
- Many people cannot afford to pay \$35 (out-of-pocket) a day for the social adult day services model and therefore are sending their family members to the medical model adult day care centers since they are covered by Medicaid.

Proposed Solutions:

- Make caregiving more affordable for the middle class by including a mix of subsidized insurance, private insurance, tax credits and deductions.
- Give stipends to family caregivers who choose to provide care themselves and Social Security credits to those who leave the workplace to do full-time caregiving.
- Provide federal matching funds for New York State Bill A#8749 that would give state tax credits to state and municipal workers who are also caregivers.
- Compensate family caregivers in a way that is similar to the foster care program.
- New York State should modify FMLA in a way similar to the Family Paid Leave Law in California enacted in 2002, where an employee funded program offers workers up to six weeks paid leave to care for an ill family member.
- Pass New York State bill A#1301 that would expand FMLA coverage to companies with 10 or more employees (versus 50 or more employees.)
- Invest in community-based programs to serve older adults.
- Medicaid should cover the costs of both medical and social model adult day care service programs.

Priority Issue #2: Support Services for Caregivers

- There is too little training to teach family caregivers how to perform difficult personal tasks or deal with complicated medical equipment or procedures.
- Family caregivers are not mentally prepared for providing long-term home care and the conflicting feelings that providing care may cause.
- The aging population in NYS, and particularly in NYC, will become more diverse in the coming years. Projections indicate that minority populations will increase by nearly 40% in the next 25 years. With diverse customs and cultural practices that make our communities richer and more complex, agencies need to be prepared to provide culturally competent services.

- Lack of funding for small community-based organizations that often serve as the first point of contact for caregivers.

Barriers:

The barriers to support services for caregivers include:

- Appropriate resources to educate communities, particularly immigrant communities, about care and services are not available.
- Federal program and funding often requires matching funds to qualify for funding.

Proposed Solutions:

- Aging providers need assistance for greater outreach and should work with religious groups, hospitals and physicians, discharge planners, etc. to be able to share services being offered.
- More supportive services for caregivers that would include: training, assistance, counseling, support groups, and educational workshops.
- HMO's and Medicare should consider supplementing and paying for supportive services for caregivers, like training, assistance, counseling, support groups, respite, and supplemental services.
- Create a central listing of caregiving resources available by area, similar to what is available in Brooklyn.
- Continue to fund and support services such as meals-on-wheels, senior centers, adult day centers, etc.

Priority Issue #3: Grandparents raising Grandchildren

- Nationally, 4.5 million children are living in grandparent-headed households. In New York City 1 out of 8 children is raised by a relative.
- One of the greatest challenges facing elderly caregivers is economic hardship.
- Only two main sources of support for elderly caregivers: foster care board payments and Temporary Assistance for Needy Families (TANF) child-only funds.

Barriers:

The barriers experienced by grandparents raising grandchildren include:

- In some instances, grandparents are not recognized as the legal guardian, making situations much more difficult.
- Education system has changed from the time grandparents raised their own children, financial needs, knowledge of legal issues, health of grandparents, language barriers for immigrant grandparents, adjusting to new parent status, and conflicts with birth parent.
- Difficult for grandparents to leave the house, especially if raising young children.
- Informal kinship caregivers are not eligible for state funded options, such as child-only TANF funds and clothing allowances.
- Grandparents are often neglecting themselves.

Proposed Solutions:

- Fund more supportive service programs for grandparent caregivers.
- Continue to support advocates and case management services for grandparents so that they are accompanied to appointments, can access legal and financial assistance, and are able to get supportive and respite services.
- Fund and support more “One-Stop Shopping” programs where a grandparent can get legal, financial, and emotional aid in one place.
- Recognize and support the need for mental health services for grandparent caregivers.
- Increase “child-only” grants.

Priority Issue #4: Palliative Care and Helping Caregivers Deal with Death and Dying

- Caregivers and service providers are often unprepared to deal with those who are nearing the ends of their lives and the pain, concerns, and needs that come with it.

Barriers:

The barriers experienced in palliative care and helping caregivers deal with death and dying include:

- Service providers are often untrained in how to care for those who are dying.
- Lack of knowledge on options available to caregiver, such as long-term care, hospice, health care proxy, etc.

Proposed Solution:

- Giving licensure for people who are qualified in bereavement.
- Public health initiative to inform people about services and options that are available.
- Require medical students to pass through a palliative care residency.

Priority Issue #5: Geriatric Mental Health Issues

- Seniors psychosocial issues need to be addressed.
- Mental health seen as taboo in many cultures, preventing caregivers from discussing their need for mental health services and engaging in supportive therapies.
- Recognizing signs of depression and need for mental health evaluation.
- People are living long enough to develop late-onset mental disorders, but the chronically mentally ill are living longer, too.

Barriers:

The barriers to geriatric mental health issues include:

- Existing care for elderly mental health patients is inadequate.
- Lack of specialized professionals to work with elderly mental health patients.
- Depression is often dismissed as not being a mental illness.

Proposed Solution:

- Recognizing that chronic diseases are highly correlated with mental health.
- Screening for mental illness should be part of health care visit.
- Better trained staff who work with elderly to identify depression and have them properly refer clients.
- Recognize the strength in having an integrated service structure of health, mental health, and aging services.
- Support the Geriatric Mental Health Act recently passed in New York State.